HEALTHCARE NEEDS OF ADULTS WITH PHYSICAL DISABILITIES LIVING IN THE COMMUNITY

RESULTS OF FOUR FOCUS GROUPS WITH RHODE ISLANDERS ON FEE-FOR-SERVICE MEDICAID

Submitted to: Center for Adult Health
Division of Health Care Quality, Financing and Purchasing
Rhode Island Department of Human Services

Prepared by: Christine A Payne, PhD
for the Health Indicator Project
Medicaid Research and Evaluation Project
March, 2001

Funded by: Center for Health Care Strategies
Princeton, NJ

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Christine A. Payne, PhD
Health Indicator Project
Medicaid Research and Evaluation Project

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I. EXECUTIVE SUMMARY

MCH Evaluation, Inc. conducted four focus groups with 32 adults on fee-for-service Medicaid. The purpose of these focus groups is to provide baseline qualitative information on:

- the quality of health care,
- access and barriers to health care,
- utilization of health care services, and
- unmet health care needs

for adults, ages 21-64, with disabilities and chronic health conditions who live in the community.

Major findings from the focus group include:

- **Twenty-nine of the thirty-two participants (90%) reported they suffer from more than one chronic health problem; nineteen of the thirty-two participants (59%) reported they suffer from more than two chronic health problems.** Diabetes, arthritis, high blood pressure, depression/anxiety, heart conditions and asthma were the most commonly self-reported health problems.

- **Persons with their own doctors experience greater continuity and coordination of medical care. Their health conditions are better managed and their overall satisfaction with the medical care they receive is high.** Medicaid enrollees who have their own doctor, whether they had their own doctor before needing medical assistance or obtained a doctor while on Medicaid, have access to the full-range of medical care.

- **Focus group participants who do not have their own doctors often have difficulty finding a doctor who will see them due to their Medicaid status.** Many of these people obtain medical care at clinics where they are seen by a rotating series of resident doctors. They experience fragmented and discontinuous medical care. **Not having one's own doctor can lead to frequent and inappropriate use of emergency department services as well as can increase the likelihood of preventable hospital admissions.**

- **For persons who lost their health, their jobs and their private health insurance, not having or being able to obtain information about Medicaid services and benefits prevents them from playing a role in managing their health problems and serves to increase their feelings of powerlessness.** The lack of information about Medicaid services and benefits is especially problematic for those enrollees who worked during their lives and who, until the time they had to end employment due to their illnesses and injuries, had experienced a sense of control and independence in their lives.

- Focus group participants reported three problematic issues concerning prescription medications. **First, there was general dissatisfaction with and confusion about generic drugs. Second, focus group participants voiced confusion about the Medicaid Program's policy concerning prescription medication refills. Some of the focus group participants stated they are not able to obtain prescription medication refills unless they pay for the refills themselves.** For some this meant either going without food or other necessities in order to purchase the medication refills or going without the needed medication. **Third, there was confusion as to the period of time in which a prescription is allowed to be filled.**

- **For many of the focus group participants, pain and depression are constants in their lives. The fourth most commonly reported health problem of the focus group participants is depression/anxiety. Mental health counseling, however, is not easy to obtain and is a major unmet need for this population.**

II. BACKGROUND

The Center for Adult Health, Rhode Island Department of Human Services, has oversight responsibilities for all Medicaid Services for adults with disabilities and chronic health conditions. All Center services are currently provided on a fee-for-service basis.

The purpose of this series of focus groups is to provide baseline qualitative information on the quality of health care, access and barriers to health care, and unmet needs for adults, ages 21-64, with disabilities and chronic health conditions on Medicaid living in the community. The information collected in the focus groups was used to develop a state-wide survey of this population to be conducted in the late winter/early spring of the year 2001.

III. METHODS

MCH Evaluation, Inc., a research contractor for the Medicaid Program in the Rhode Island Department of Human Services, conducted the focus groups. MCH Evaluation convened a planning group to determine areas of discussion for the focus groups and to design questions to address these areas. The planning group wanted to address the following issues:

- Access to Medicaid
- Service Utilization
- Quality and Adequacy of Care
- Unmet Need
- Suggestions for Change

A draft set of questions was developed to address these issues and submitted to the planning group for review and comment. Revisions were made and a final set of questions was designed. (Appendix 1.)

From the computerized Medicaid Management Information System (MMIS), records were selected for persons:

1. ages 21-64
2. on fee-for-service Medicaid
3. whose only source of health insurance was the Medicaid Program
4. enrolled in the Medicaid Program for at least 300 days

5. who had at least one hospitalization and/or emergency department visit in the calendar year 1998
6. who are not identified as having Severe and Persistent Mental Illness
7. who are not identified as Mentally Retarded or Developmentally Disabled
8. who had not been hospitalized or had an emergency department visit for a principal diagnosis of mental disorders (ICD-9 codes 290-319)
9. self-identified as White, African American, or Hispanic
10. whose primary language is self-identified as English
11. who are residents of the city of Providence

Selection criteria 1 and 2 identified our population of interest. Selection criteria 3-5 identified persons who have received Medicaid services and benefits. Criteria 6-8 eliminated persons for whom participating in a focus group setting could be difficult for themselves, for the other focus group participants and could pose problems for the focus group facilitators in achieving the focus group goals. Criterion 9 allowed separate sessions to be conducted with African American, Hispanic and White populations. Each groups' facilitator was a member of that race/ethnic group. One intent of the focus group series was to investigate difference in experience with the Medicaid Program for persons of different races and ethnicities. Though we found the emphasis placed on issues of concern to differ from group to group, the issues that emerged were the same in all groups. As such, we do not make distinctions based upon race or ethnicity in the presentation of results. Criterion 10 increased the ease of conducting the Hispanic group. However, the facilitator of the Hispanic group was fluent in Spanish and a few of the participants spoke Spanish in expressing their opinions and comments. Criterion 11

made transportation to the focus groups easier for participants and kept the expense of conducting the focus groups within the program's budget.

Based upon the resulting list of potential participants, recruitment/screening phone calls were made. Each person was asked twelve questions to screen for appropriateness ad to assign them into a race/ethnic focus group (Appendix 2). The number of persons who were willing to participate in the focus group sessions allowed us to plan a fourth group. This fourth group was not specific to any race or ethnicity. A total of 32 persons participated in 4 focus groups.

A reminder flyer was sent to participants a few days before the focus groups were held (Appendix 3). Four focus groups were held in October and November of 2000. The sessions were held in the late afternoon/early evening and a meal was served at each session. An introductory statement was read (Appendix 4) and a facilitator asked the open-ended questions. The focus groups were taped and a recorder took notes (Appendix 5). Participants were paid $50 for their participation and they were reimbursed for child care and transportation.

At the end of two of the four focus groups, representatives from the Medicaid Center for Adult Health were present to answer participants' questions about the Medicaid Program. The tape recording of each meeting was transcribed, the transcriptions were reviewed, major issues were outlined and quotations were selected to illustrate the opinions of the participants.

IV. RESULTS

A total of 32 persons participated in the four focus groups. Twenty-five percent of the participants were male and 72% were minority. Twenty-nine of the thirty-two participants (90%) reported they suffer from more than one chronic health problem; nineteen of the thirty-two participants (59%) reported they suffer from more than two chronic health problems. Diabetes, arthritis, high blood pressure, depression/anxiety, heart conditions and asthma were the most commonly self-reported health problems. The following four tables present a summary of participants' characteristics for each of the four focus groups. Each table presents a breakdown of participants' characteristics by sex, age, self-identified race/ethnicity, self-reported health problems and a count of the number of self-reported health problems per participant.

Table 1: Participant Characteristics of Focus Group One: African American

Number of Participants	7 (Male: 1; Female: 6)
Ages	49, 27, 55, 57, 51, 51 56
Median Age:	51
Self-identified Race/Ethnicity:	African American
Self-reported Health Problems	diabetes, high blood pressure, anemia, heart condition, asthma, arthritis, lupus, hypertension, amputated leg, amputated toes, migraine headaches, high cholesterol, chronic constipation, degenerative bone disease, angina, ruptured disks.

Number of Participants who self-reported more than one health problem: 6
Number of Participants who self-reported more than two health problems: 5
Number of Participants who self-reported more than three health problems: 2

Table 2: Participant Characteristics of Focus Group Two: Hispanic

Number of Participants	8 (Male: 1; Female: 7)
Ages	55, 55, 27, 53, 62, 35, 36, 58
Median Age:	54
Self-identified Race/Ethnicity:	Hispanic (5)/Puerto Rican (3)
Self-reported Health Problems	hepatitis C, diabetes, chronic arthritis, nerves, arthritis, breast cancer, depression, anxiety, thyroid problem, slipped disks, high blood pressure, club foot, back problems, asthma, migraine headaches, thrombosis, spinal cord tumor

Number of Participants who self-reported more than one health problem: 7
Number of Participants who self-reported more than two health problems: 6
Number of Participants who self-reported more than three health problems: 5

Table 3: Participant Characteristics of Focus Group Three: White Non-Hispanic

Number of Participants	11 (Male: 3; Female: 8)
Ages	44, 55, 62, 63, 42, 58, 56, 55, 60, 46, 57
Median Age:	56
Self-identified Race/Ethnicity:	White non-Hispanic (9), Cape Verdian (1), Native American (1)
Self-reported Health Problems	emotional problems, "slow", elbow surgery, anemia, fibromalagia, heart condition, diabetes, high blood pressure, anxiety, cramps in leg, arthritis, overweight, asthma, thyroid problem, stroke, av block in heart, neck injury, liver problems, hearing problem due to infection, knee replacement, degenerative arthritis, heart attack, fused vertebrae, depression, post traumatic stress, OCD, edema, sleep apnea, ovarian cancer

Number of Participants who self-reported more than one health problem: 11
Number of Participants who self-reported more than two health problems: 8
Number of Participants who self-reported more than three health problems: 4

Table 4: Participant Characteristics of Focus Group Four

Number of Participants	6 (Male: 3; Female: 3)
Ages	62, 60, 48, 44, 52, 30
Median Age:	50
Self-identified Race/Ethnicity:	Cape Verdian (1), Philippino (1), African American (2), Native American (2)
Self-reported Health Problems	anxiety, high blood pressure, leaky valve, legally blind, multiple sclerosis, HIV positive, depression, "back and side", "ghost cells" due to fall. (Facilitator's note: Two of the participants were unable to provide an understandable response to the question of health problems; facilitator's perception of health problems of persons in this group included developmental disabilities and alcohol dependency.)

Number of Participants who self-reported more than one health problem: 5
Number of Participants who self-reported more than two health problems: 0
Number of Participants who self-reported more than three health problems: 0

A. ACCESS: ENROLLING IN MEDICAID

The people who participated in the focus groups suffer a wide range of physical, emotional and developmental disabilities and chronic conditions. Some focus group participants have lived with these health problems since childhood. Others became ill or injured as adults. Some participants have received public financial support throughout their lives and were enrolled in the Medicaid Program when their health became problematic. Other participants were employed until an illness or injury forced them to stop working. For some of the latter, the loss of employment meant the loss of private health insurance. Enrollment into the Medicaid Program was often precipitated by a medical crisis. Most of the focus group participants were assisted or directed in the enrollment process by medical providers or social workers.

I've been on it (Medicaid) since 1972 because I have problems with both my legs and I am loaded with arthritis. I was on another program but when I got to a certain age they dropped that program, they automatically put me on Medicaid and so I've been on it since.

I go started in 1985 when I was stabbed twice. I sued to be the supervisor at… and I had 80 men and 15 women (working for me) and one of the guys stabbed me twice. I went to the hospital. I was in the intensive care (unit) for two weeks because it punctured my lung. And I met the social worker there, a very good guy, and he got me on (Medicaid).

I've been on (Medicaid) for a couple of years. Do you know how I found out? I was on welfare. I was having (health) problems. It (welfare) was running out and the social worker said why don't you apply. So I did and I got on it with really not too much of a problem.

I've been on Medicaid for about a year and 3 months. The reason I got on is I have a heart problem. At first it (having the heart problem) was kind of hard, but not it's okay because I can go to the doctor when I want to.

Enrolling in the Medicaid Program was not always quick and sometimes was accompanied with disrespectful treatment directed at the enrollee.

I heard about it (Medicaid) when I got sick. I use to work so my insurance run out. So here I am with no insurance to cover me. I had to leave the job so I had to apply to Medicaid. It took years. I had developed a tumor on my spine. We had a lot of problems. A lot of meetings with doctors. They called the Medicaid office. I was in the hospital and when they were ready to throw me out of the hospital, there was no one to cover me. Here I am half blind, couldn't walk or talk, couldn't do nothing for myself because this tumor took completely my whole system. In bed, couldn't do nothing. I had a doctor. She fought for my Medicaid so I could have my surgery done. Finally two days before I was (to be) discharged from the hospital, Medicaid came through and I had all the problems taken care of. I had surgery done and I've been on Medicaid ever since.

My doctor told me to apply because I would be disabled more and more with age. And that's how I found out. At that time I was working and I knew Welfare existed. I didn't know about SSI. He (the doctor) did everything. He's an exceptional doctor. He brought everything to his office… You will probably never hear again in your life… (the doctor) going and blasting out the people that had decided to do another x-ray and put my body into static stress where I could not move anything. And they (Medicaid) still turned me down. And he (the doctor) is the one (who got me medical coverage). I never had a lawyer. He (the doctor) turned into a lawyer in front of my face… It took me two years to get on.

Well, I was working and then in 1988 I became a diabetic and things kind of changed around. Then I wasn't working and (I was told) you should apply for welfare. So I tried that and I was on it for a month and then landed in a hospital. While there I was shocked. I was in the (hospital) room (with three other patients) and somebody said to me (loudly from across the room) is someone coming from welfare? You're about to be cut off. I said they told me in another month. She said that's not my business. She says who's going to pay for all this while you stay here? I don't know. She said, well I don't know what to tell you. If you find out something, give me a call downstairs tomorrow. (Then the person left the room.) Everybody in the room was like, looked at me and they all looked away and they were furious. Why didn't you say something. I said I didn't know what I was supposed to say. She shouldn't talk that way. I said I thought it was wrong but I didn't know I was supposed to say anything. I just didn't understand why she did that. I thought because I was kind of being scolded and for having to be ill and I'm sorry. If I had my way I would have loved to be well.

B. ACCESS: OBTAINING INFORMATION ABOUT MEDICAID SERVICES AND BENEFITS

The Medicaid program offers little information to enrollees about services, benefits or available medical providers. **The lack of information about Medicaid services and benefits causes confusion and frustration and has the potential to exacerbate health problems.**

Everybody had their individual (health) problems. Now when you apply, they know your problems. Well how come there isn't a package sent to you for your problem or where you can go. Where and who's available to you. Nobody tells you anything.

Everybody tells you, you are eligible for this and you are eligible for that but then you say to them how do I get on there? Oh I don't know and that's the end of the conversation.

I was trying to get in touch with somebody. When I first got my card, it gave all the information with numbers that I can call, okay, which sounded very, very, very easy indeed. We know I'm dumb but I'm not that dumb. It was a couple of times that I called numbers and it was like I didn't know where to call them up. They give you the numbers to call and you're not talking to anybody that's breathing on the other end. It's called tape, tape, tape, tape, tape. It's like all the humans die and left the machine there. By the time you're done, you are really frustrated and that is the hardest part for most of us, I would say, to try to get information. Yes, it's hard. Like I say, I know I'm a little dumb, okay but if you put a telephone number in front of me and say well okay now if you want certain information for this blah, blah, blah, you call this here number. So now you get to call that number and it's like you have to go (through) about twenty minutes of red tape. I'm 62 years old. My brain doesn't go any farther than five minutes and then it's gone. Then I forget what I was getting.

You try to call that number and you don't get through to that number. So you're on the phone for half and hour and you have to go to the bathroom. So then you either miss it or you go to hang up and start all over again.

You know you're eligible to get a wheelchair… They tell you you're eligible to get a wheelchair. You're eligible to this but they don't tell you where to go. They just tell you, you can have it.

I was told yesterday, my doctor told me, I need one (a humidifier) because I have a slight problem at night. I have a tendency if I'm too relaxed and there is not enough air I stop breathing. I have sleep apnea. And he told me I should get one but VNA told me they don't think I was eligible. And then someone else said yeah, you are. But I don't know who to call or who to go to. This is why I'm saying, I need a pamphlet.

C. THE IMPORTANCE OF HAVING YOUR OWN DOCTOR

Access to needed medical care and services is most often facilitated by medical providers, medical institutions and social workers. **Focus group participants who have their own doctor, whether they had their own doctor before needing medical assistance or obtained a doctor while on Medicaid, have access to the full-range of medical care.**

I'm grateful I get my medicine. I have a good doctor. My blood pressure is high and my doctor takes care of me good. And the Medicaid program takes care of it.

No pretty much I'm all set. I have a good doctor that takes care of me. And I get the right prescriptions and things that I need.

I don't have a problem because all the time I see the same doctor… And for 8 years I go to the same doctor and all the time while I have appointments, my doctor is over there waiting for me before I go there. I don't have a problem.

(When sick) I go to the health center and I speak to the nurse and tell them what's wrong with me and she tells me to go in and my doctor is always there so I have no problem.

(When sick) I usually page my doctor and I have a code number. She calls me right back. I tell her how I feel, what I got. She calls the emergency (department) and when I go to the emergency (department) I don't have to wait. And she knows that and they know that. I go there and I say I'm sick and they see me as soon as possible… So when I call her, she calls and tells them I have my patient coming in and check her immediately before her headache goes up.

For those focus group participants who do not have their own doctor, finding a doctor and getting medical care can be difficult.

I couldn't get an appointment. I need to find a doctor… Depending on the medical insurance you have, they don't take that medical insurance and such and such. Just saying that you have medical assistance, their tone of vice changes.

I'll get on the phone (to a doctor's office) and they would be so nice to me and as soon as I say what kind of medical I have, it's like their tone of voice changes completely or right away they'll tell you "oh, we don't take that kind of medical here but we can tell you

where you can go and they'll take that medical." Personally it makes me feel that I am not good enough. You know what I mean? It's like we get treated like second hand or something. It makes me feel that I'm not getting the treatment that I should get just because of what king of medical I have.

When I went to the emergency room, he (my MS doctor) happened to be there and I was the only patient of his that he had that had my coverage (Medicaid). When I was diagnosed with MS… that's when his nurse just told me that he was going to be my doctor. He specializes in MS. I got whatever I needed. Like when I was first diagnosed with MS I couldn't walk too good so they gave me a wheel chair and then after I started physical therapy I had the crutches and I have a cane. So the doctor that I had for my MS, he was the number one doctor in the state, but he's left the state and went on to Baltimore for more research. I called his office and I cannot get an appointment there with any other doctor because of the coverage that I have.

Maybe Medicaid could get or hire a few doctors for our kind of medical (insurance) so that when we need the help, at least Medicaid has those doctors for out kind of medical (insurance).

The focus group participants have serious and often multiple medical problems that require constant management and care. Not having a regular doctor who is knowledgeable about their personal medical history is frustrating. For persons with chronic and multiple health problems, continuity of care is essential for the successful management of their conditions.

I went from doctor to doctor (in a hospital clinic), which has me very annoyed because they always ask the same. What do you have? What are you here for? I mean, you have one doctor, she already knows what you have. That use to make me so annoyed. I went to the director and said I want one specific doctor, a medical doctor that deals with me. I cannot come here every week and see a different doctor telling them what I have.

Now things are always changing so now you've got different people all the time whereas when you have your own doctor he knows you from the beginning. He knows your history. He knows what's going on.

Some of the focus group participants who do not have their own doctor find themselves not only in the situation of being treated by different doctors when they go for regular medical appointments, they find themselves receiving medical care in medical

institutions in which resident doctors provide care. It appears to some focus group participants that the resident doctors know less about their conditions than they themselves have learned over the course of their illnesses.

What I don't understand about Medicaid is why it is that only particular certain doctors will accept you, not all doctors? I mean, you got to go to those clinics. Why can't you get a private doctor of your choice? A private doctor that knows what you need. For instance, myself, with the MS going to a clinic and the person that I see is not a doctor yet and I just don't like the feeling of being a guinea pig. I'd like the feeling of someone supposedly knowing what they're doing for me. But they're actually learning off me. Whatever is bothering me okay this is what they're going to try to figure out or try to help me. But I mean, they're learning from me. They're learning from me instead of knowing what they're doing with me. Because of the coverage, there's not too much you can do about it. You just have to grin and bear it.

(What would make things better for you?) With real doctor. Because the students have, I think it's 16 students for one real doctor. Everything you say to the doctor, the doctor go to the real doctor to consult and you know they make mistakes. I had a bad experience with that.

D. EMERGENCY DEPARTMENT VISITS

Most focus group participants were satisfied with the treatment they received during hospital stays. The same is not true for emergency department visits. **Many of the focus group participants view going to the emergency department as sometimes necessary to obtain medical care when health problems become acute or when they know of no other recourse. Many use the emergency department for primary care because they do not have a doctor who will see them for urgent, non-emergency care. However, most expressed dread about making such a visit.** Focus group participants told of how they would put off going to an emergency department hoping the problem would resolve itself and how, after waiting for hours in an emergency room, they would sometimes leave without having received medical attention. The major complaint about emergency department visits is that the wait is too long.

But if you really need medical assistance, go to the emergency. It's the only way you're going to get any kind of help.

One year I went to the emergency room at least 20 to 25 times. I was admitted every time I went.

Sometimes I try to bear with it (and not go to the emergency room) because if you go to the emergency room, you can plan on camping out there at least 7 or 8 hours. That's the most aggravation. If you go there in the morning, you can figure on being there at least dinner time.

When I get sick, I go there (the emergency room). They said i , all day. All day and I don't like it. Staying there all day. And when I leave out of there at night time, I walk home and I sit down for a while and get my breath and make it on home and close to home I stop again and sit down and rest. And then I make it home then after that.

Well, in the emergency room… passed one hour, two hour, three hour and you're still there. One day I was there waiting for the doctor, waiting. I said to the nurse, I've been here since two o'clock in the afternoon. Was eight o'clock in the night. And I said I'm here. I need help because I have big, big headache. And she say, wait a minute. Next, it's 9:30, I put my clothes on, I go home.

E. MENTAL HEALTH SERVICES

The focus group participants suffer a wide range of physical, emotional and developmental disabilities and chronic conditions. For many, pain and depression are constants in their lives. The manner in which depression is dealt with varied widely among the focus group participants from distrust of mental health services and attempting to deal with their depressions themselves, to using drugs and alcohol, to seeking mental health counseling. **Mental health counseling is not easy to obtain and is a major unmet need for this population.**

I need a psychiatrist and I can't have one. So it's kind of hard for something like that. This is what I need and is ay what medical insurance I have… they tell me sorry we're not taking that insurance or we're not taking new patients. They tell me about the Providence Center. The Providence Center offers the mental health (counseling) that you need. Medicaid only pays 12 sessions so after your 12 sessions are up, you get discharged and you haven't worked out your problems. So then you have to schedule another intake, go for another orientation, and find somebody else and talk to them and by the time you explain what your problem is, your sessions are over.

Sometimes it's better to work it out on your own because everything becomes a part of a record and you find yourself looking for a service and they bring that particular part of the record up that will make you ineligible for that service depending on what your problem was when you went and what you spoke about. Even if you have been satisfactorily cured or calmed down or whatever if a lot of instances that can come back to haunt you. And I'm not saying don't do it. If you need help, if you have to stand on the corner and scream to the top of your voice, you get help and deal with the rest later. Don't ever turn down help for that, your never or whatever.

I went to a psychologist through the years because I tried to kill myself when I was going through my illness. I was in so much pain and they couldn't find what to do with this pain. This pain was driving me nuts. I couldn't think straight. I would sit home with a bottle of aspirin, 300 aspirins or painkillers, sit there at 5 in the morning and 12 in the afternoon I wouldn't have one pill left. I was popping pills like no tomorrow. It's not because I wanted to pop the pills, it was the pain I had. I would start shaking. I would start sweating. I would start getting bad ideas. One night the pain hit me so bad, I didn't have one pill. I didn't want to go to the emergency. I said, God I'm going to finish with this. So I went to my window to jump from the 6th floor. Do you know what saved me? I

had a dog. She (the dog) went and pulled my son out of bed. She pushed my son out. Now my son knew my condition and he knew that I had told him that one day I was going to kill myself. So he ran through the room. He said you of all people. He pulled me back up and he said now you need to go see a psychologist or psychiatrist. I was put in the hospital for 3 weeks. I didn't want to go in because I feel psychiatrist is only for crazy people but it's not. I had a bad depression. I'll tell you, they helped me a lot, a whole lot to overcome my illness. I was seeing a psychologist every week until I dropped it myself. It helped me a lot. The doctor was so good and she really worked so hard on me. She worked very hard to get me over these bad ideas and live a happy life. The pain was just so immense, I just couldn't handle it.

F. EYE CARE AND DENTAL CARE

With respect to eye care and dental care, the focus group participants were frustrated by the amount of time they needed to wait in order to obtain services. Some of the focus group participants experience having to wait the required time-interval between obtaining repeat eye and dental services to be especially burdensome.

Eye Care

I've got bifocals so my eyes are bad. So I have to see. My other pair I couldn't even read so I needed another pair and I had to pay for them because (otherwise) I had to wait 2 years before I could get (new) glasses.

His insurance give out and when he was told to get his glasses, the insurance give out, and he had to wait. I guess he didn't get them for three months.

I have a problem. I have a problem with the eye doctors because I go to an eye doctor but I can't, when you're on Medicaid you can only go every two years. But if I went to my retina specialist I can go to him five or six times in the year but I cannot go to my regular eye doctor. Now I have no retinas in my eyes so I have to have my eyes treated and I have to get my eye glasses changed at least once a year. I have just the veins in the eyes, no round circles, so in order for me to keep up with it I have to go to the retina doctor all the time instead of my eye doctor to keep getting my glasses changed. Now that doesn't make sense. I went this year. I can't go until the year 2002 to get another pair of glasses and my doctor is upset about it… If I can go to a specialist that costs more why can't I go to a regular eye doctor once a year instead of every two years?

My doctor said it was imperative that I go because of my eyes but they (Medicaid) send back a letter stating every two years. That's why I went two years ago and I have to go this year. Now I can't go back and it's on my record. They showed me in red. I can't go back until February of the year 2002.

Dental Care

I went to the dentist 2 weeks ago and… sent some papers to the Medicaid to see if they approve it. I'm still waiting.

They have to make you wait. Once they pull your teeth out… Why you have to wait 3 to 6 months (to get dentures)?

About a week ago, I went to the dentist. I only have 12 teeth anyway but I want to take them out because I have a problem eating. So the dentist I went to, he gave me a referral to an oral surgeon and he said come back in two months and I'll start fixing your teeth. So I guess he's been working with Medicaid because as soon as he heard I had Medicaid he said no problem. He said it's usually 3 months but he would work with me because I told him I didn't want to be without teeth for too long. Like I said you need 2 or 3 months for your gums to heal before they try to make a plate because otherwise you'd have a lot of problems.

I have to have a crown now and I can't have it until I can have a new x-ray because I had one four months ago.

They would make the top (dentures) but they wouldn't make the bottom. Medicaid don't pay for it.

G. PRESCRIPTION MEDICATION

Though sometimes there was a wait to receive durable medical equipment such as a wheelchair, cane or hospital bed, most of the focus group participants had little difficulty obtaining the durable medical equipment they needed. There is, however, much confusion concerning prescription medications. For many of the participants, the chronic nature of their health problems requires they take a particular prescription medication regularly, month after month, year after year. Further, many of the participants have multiple health conditions that require taking numerous prescription medications. Twenty-nine of the thirty-two participants (90%) reported they suffer from more than one health problem; nineteen of the thirty-two participants (59%) reported they suffer from more than two chronic health problems. **Given the seriousness and the chronic nature of the focus group participants' health problems, prescription medications are one of their major lifelines.**

One issue brought up in the focus groups was a general dissatisfaction with and confusion about generic brand drugs. In some cases people were so confused about generic brand drugs they didn't take needed medication or waited until they could obtain the money to purchase the brand name drug prescribed to them.

Generic according to all the books that I've read is not ever the same thing as the regular. It is a portion. It will even tell you how much of a portion is in your pill and what the filler is to the medicine that you are taking. So it is impossible for a generic brand to be as good as the regular.

They (the pharmacists) only give it (generic drugs) to you because they will not be paid. They will not be paid if they give you the regular brand if there is a generic for it. And there are some pills that are 17 to 22 generics for. So imagine someone 70 years old that knows her pill by the color pink and next month they changed that some pill to the color blue. And now she is confused and she is not taking that pill.

If the doctor gives you a prescription, it's because that is what you need. It's like she was saying, why would you try to give me something else and it wasn't what the doctor prescribed to me? They'll (the pharmacists) come from behind the counter and go and look at the shelves and tell you well this has this and that in it. Try to give you a generic brand, because the medical (insurance) that you do have doesn't cover the prescription. (You have to pay for it) out of your pocket. And me a single mother of eight kids. I ain't got no extra change in my pocket. I barely make my bills now. So either I have to go without the prescription or just wait until I get my check to get the prescription.

I take a pill for my heart and every time I get the prescription filled I have to make sure it's the same size pill because if it isn't, it doesn't do nothing for me. I land in the hospital. I mean if you're getting a little teeny weenie pill, you know, for say five years or four years or whatever and then all of a sudden you get the same prescription and the pill is two times bigger. Why should it be changed in midstream, you know, why should they change it?

Okay, there's something that I can't understand. I take some dope to make me urinate, okay. Without pills, I can't urinate. I got to go right to the hospital. They've got to put a catheter and all the other things. Medication that I was on, regular medication, a little round red pill. That was working fine… went down to get my medication and brought it home and see a small brown pill. Looked like a little bean. I brought it back to the pharmacy and I said, I think you gave me the wrong pill here. For the last two years I've been on this other pill and it works fine… this pill that I'm taking now is a pink pill and it's like a capsule. He says that's okay, he says it's the same identical pill that you were taking but it's a generic pill. I said well, okay, why do I get a generic pill. Well because the government won't pay for the other. … I say it's not working good at all for me. He said take one pill. Now I take two. What the other pill was doing for me, now I got to take two. Went back to the pharmacists and I said, you know, if this is supposed to be the same pill, why isn't it working for me. I'm finding that I got to take two pills now, more than I had before, I took the one pill. Well, we can't do anything about that. You got to take this here. I said well now it's going to cost them twice as much for this generic pill because I got to take twice as much in order to do any good for me. I don't understand that at all.

A second problematic issue concerning prescription medications is confusion about the Medicaid Program's Pharmacy Services policy. The Medicaid Program's manual states that except for emergency situations, all medication is dispensed on the basis of a written prescription and a maximum of 5 refills is allowed for those medications required for the continuous treatment of chronic conditions. For persons with chronic health problems, a prescription with 5 refills can provide needed medication for a six month period.

However, some of the participants in the focus groups stated they are not able to obtain the refills specified on their written prescriptions unless they pay for it themselves. They stated their pharmacists told them the Medicaid Program does not pay for refills. Not being able to obtain medication refills negatively impacts the ability of persons to manage their health conditions. Focus group participants worry about how to get the money needed to pay for refills or they go without needed medication. In order to obtain needed medication, some of the focus group participants who take prescription medications for chronic health conditions contact their medical provider or go to their medical provider's office every month. This places an additional burden on people who are already leading difficult lives. Some of the participants, however, have found ways around this situation.

I had a bunion removed in February and they (the doctor) had given me pain medication with a refill and they (the pharmacy) said that Medicaid would not pay for the refill. They paid for the original but they wouldn't pay for the refill so I had to borrow here and there to get my pain medication. I don't understand that. But I know next time to tell the doctor to write double. If he gave me 20 pills with a 20 refill, next time I would explain the situation to him and say could you write the prescription out for the 40 because I think that is what I'll need.

She (the doctor) is only in once a week and I'm a diabetic and I've got high blood pressure. I'm on pills and I have to wait until she (the doctor) comes in (to the office) tomorrow to get another refill. And I don't go back there (to the doctor's office for a medical exam) until February.

Two years ago something started happening with me with one of my medications. The only way, like if your doctor write like two refills, I can't get those two refills unless I pay for the whole prescription, the first one, the second one and the third one. Otherwise, I don't get it. I can get the first one but that's it but I won't get the two (refills) that were prescribed for me. My doctor has done this a couple of times because if he's going out of the country like he did for six months, he wrote me out a prescription like that, and that's how I found out and I was without (medicine) because he was out of the country.

So now, I told my doctor about it so what he does, he writes me two prescriptions with no dates on them. He doesn't put refill on either one of them and this way I can get them and I don't have to pay for them. But it shouldn't be like that because if you lose one, you're dead.

There is also confusion among focus group participants as to the period of time in which a prescription is allowed to be filled. The Medicaid Program's Pharmacy Services manual allows a prescription to be filled for one year after the date of service.

[Person 1] I found out something from my pharmacist… After seven days, they (the pharmacy) won't fill it. They won't fill the medication anymore. They won't honor it and that's a mind blower. [Person 2] That's what they did to me. All of a sudden, I think it was good for six months at one time. Then it went to ninety days and then all of a sudden it went to three days and now we can't fill this time. You have to get another (prescription). [Person 3] No, it was seven days, seven days now. But you see how do we know this? No one gives us any notices. There's nothing written, nothing in the newspaper. We don't get a flyer or anything.

V. FINDINGS AND RECOMMENDATIONS

A finding common to all four focus groups is that Medicaid enrollees who have their own doctor, whether they had their own doctor before needing medical assistance or obtained a doctor while on Medicaid, have access to the full-range of medical care. **Persons with their own doctors experience greater continuity and coordination of medical care. Their health conditions are better managed and their overall satisfaction with the medical care they receive is high.**

Focus group participants who do not have their own doctors often have difficulty finding a doctor who will see them due to their Medicaid status. Many of these people obtain medical care at clinics where they are seen by a rotating series of resident doctors. As a result, they experience fragmented and discontinuous medical care. **Not having one's own doctor can lead to frequent and inappropriate use of emergency department services and can increase the likelihood of preventable hospital admissions.**

A second finding common to all four focus groups concerns the focus group participants' inability to obtain information about what services and benefits the Medicaid Program covers. This lack of information causes confusion and frustration and can exacerbate health problems. The lack of information about covered services and benefits is especially problematic for those Medicaid enrollees who worked during their lives and who, until the time they had to end employment due to their illnesses and injuries, had experienced a sense of control and independence in their lives. **For persons**

who lost their health, their jobs and their private health insurance, not having or being able to obtain information about Medicaid services and benefits prevents them from playing a role in managing their health problems and serves to increase their feelings of powerlessness.

A third finding, and by far the most problematic for the majority of the focus group participants, concerns prescription medication. Given the seriousness and the chronic nature of the focus group participants' health problems, prescription medications are one of their major lifelines. For many of the participants, the chronic nature of their health problems requires they take particular prescription medications regularly month after month, year after year. Further, many of the participants have multiple health conditions which require taking numerous prescription medications. We found there to be three problematic issues concerning prescription medications. First, there is general dissatisfaction with and confusion about generic drugs. Second, there is confusion about the Medicaid Program's policy concerning prescription medication refills. Some of the focus group participant stated they are not able to obtain prescription medication refills unless they pay for the refills themselves. For some this meant either going without food or other necessities in order to purchase the medication refills or going without needed medication. Third, there is confusion as to the period of time in which a prescription is allowed to be filled. **The distribution of a written brochure explaining in simple language the Medicaid Prescription Medication Policies would serve to lessen the confusion concerning prescription medications and allow Medicaid enrollees to better manage their health problems.**

Finally focus group participants find it difficult to obtain adequate mental health counseling. Currently, mental health counseling is not available to many populations throughout the county. However, this lack is particularly for this Medicaid population. The focus group participants suffer a wide range of physical, emotional and developmental disabilities and chronic conditions. Twenty-nine of the thirty-two participants (90%) reported they suffer from more than one chronic health problem; nineteen of the thirty-two participants (59%) reported they suffer from more than two chronic health problems. **For many of the focus group participants, pain and depression are constants in their lives. The fourth most commonly reported health problem of the focus group participants is depression/anxiety. Adequate mental health counseling is a major unmet need for this population.**

Appendix 1: Focus Group Questions

FOCUS GROUPS
ON ADULTS WITH PHYSICAL DISABILITIES ON MEDICAID LIVING IN THE COMMUNITY

PURPOSE: To measure the quality of health care, access and barriers to health care, and the extent of unmet need for adults, ages 21-64, with physical disabilities on Medicaid living in the community.

ACCESS TO MEDICAID

1. a. How did you first hear about medical assistance/Medicaid? What happened when you tried to apply?

   b. How do you find out if Medicaid covers a service or provides a certain benefit? Is there someone who helps you get a service or helps you with your health problems?

2. Have you ever needed medical care and not been able to get it? What happened? (e.g., transportation, money, lack of information as to where to go, etc.?)

SERVICE UTILIZATION/QUALITY AND ADEQUACY OF CARE

3. a. Do you have your own doctor, someone you see regularly for medical care? Where do you go for medical care?

   b. Have you ever tried to make an appointment with a doctor for a check-up? What happened when you tried to make an appointment with a doctor for a check-up? How long did you have to wait? How did the doctor treat you? Did you understand the doctor's instructions?

4. What do you do when you are sick and need to see a doctor right away? Have you ever used the emergency department for other than an emergency? Why? What was that like?

5. Have you ever been hospitalized? What was the reason for your hospitalization? Were you satisfied with your stay?

6. Have you ever tried to fill a prescription? Get dental care? Obtain medical equipment? Obtain other specialty care? Have you ever felt so depressed or anxious that you sought medical care? Did you get the help you needed?

UNMET NEED AND SUGGESTIONS FOR CHANGE

7. How can the Medicaid program better meet your needs or improve services? Are there any services or equipment that you need that would help you stay healthy or make your life easier? Do you think your health care needs are going to change as you get older? How? In what way?

METHODS: There will be three focus groups with from 7 to 9 participants in each. Each group will be comprised of a specific race/ethnic group -- White non-Hispanic, Black non-Hispanic, and Hispanic. In addition to the above questions, we hope to discern whether the issues of trust and language create significant barriers to obtaining medical services for members of various race/ethnic groups.

Appendix 2: Phone Call Protocol Screening Sheet

FOCUS GROUPS

SCREENING QUESTIONS

Name of person: _____

Address: _____

_____

_____

Phone: _____

Date of call: _____

ID#: _____

Hello, this is Holly from the Medicaid Office. We are going to be conducting a series of groups for the Medicaid Program at the Rhode Island Department of Human Services. We want to find out what you think about the Medicaid Program. Specifically, we want to learn if the Medicaid program helps you to meet your health-related needs.

Your ideas and opinions will help us improve programs for adults with health problems. All information is kept confidential. Each person will receive $50 for his/her participation. Are you interested?

If so, I need to ask you a few questions for group placement

a. How old are you? _____

b. What is your Race/Ethnicity? _____

c. What is your most serious health problem?

_____

_____

d. Do you have other health or medical problems? List

_____

_____

_____

_____

The groups will be held at the Holiday Inn in downtown Providence.
We will hold the groups in the early evening and will provide a light supper.

Are you available to attend a group on (cite appropriate date and time): _____
(yes/no)

****

White non-Hispanic group DATE: _____ TIME: _____
Black non-Hispanic group DATE: _____ TIME: _____
Hispanic group DATE: _____ TIME: _____

****

1. Will you need transportation? We will pay for a cab. _____

2. Do you have any children? Will you need childcare? _____
   List ages of children. _____

3. Are there special equipment or accommodations you need in order to participate?
   _____
   _____
   _____
   _____
   _____

4. Do you have any questions for me?
   _____
   _____
   _____
   _____
   _____

Thank you for taking the time to talk with me today. If you are selected to participate in the group, we will call you back.

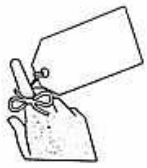
5. Is this the best phone number at which to reach you? _____

Holly's comments on this call:

_____
_____
_____
_____
_____
_____

Appendix 3: Reminder Flyers

❧ *A Second Reminder About The Focus Group* ❧



Thank you for signing up for our
Medicaid Focus Group!

We need <u>your</u> opinions and comments about the
Medicaid Program's services and benefits

When: Wednesday, October 18, 2000

Where: Holiday Inn in Downtown Providence
Promenade Room

Time: 6:00 pm to 8:00 pm

🕒 please come 15 minutes early, because we will start right at 6

We will pay for transportation and childcare

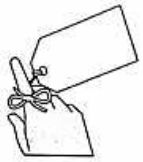
**** A Light Dinner is provided ****

→ *You will be paid $50.00 for your participation in the focus group*

Please call Holly at 462-6367 if you have any questions.

☺ Sponsored by The Center for Adult Health ☺
Department of Human Services

A Reminder About The Focus Group



Thank you for signing up for our
Medicaid Focus Group!

We need <u>your</u> opinions and comments about the
Medicaid Program's services and benefits

When: Wednesday, October 25, 2000

Where: Holiday Inn in Downtown Providence
Promenade Room

Time: 4:00 pm to 6:00 pm

please come 15 minutes early, because we will start right at 4

We will pay for transportation and childcare

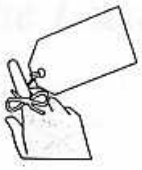
**** A Light Dinner is provided ****

➔ You will be paid $50.00 for your participation in the focus group

Please call Holly at 462-6367 if you have any questions.

☺ Sponsored by The Center for Adult Health ☺
Department of Human Services

❧ *A Reminder About The Focus Group* ❧



Thank you for signing up for our
Medicaid Focus Group!

We need <u>your</u> opinions and comments about the
Medicaid Program's services and benefits

When: Wednesday, November 8, 2000

Where: Holiday Inn in Downtown Providence
Promenade Room

Time: 6:00 pm to 8:00 pm

🕒 please come 15 minutes early, because we will start right at 6

We will pay for transportation and childcare

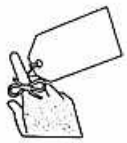
**** A Light Dinner is provided ****

➔ *You will be paid $50.00 for your participation in the focus group*

Please call Holly at 462-6367 if you have any questions.

☺ Sponsored by The Center for Adult Health ☺
Department of Human Services

❧ *Date, Place & Time Change for The Focus Group* ❧



Thank you for signing up for our
Medicaid Focus Group!

We need <u>your</u> opinions and comments about the Medicaid Program's services and benefits

When: Thursday, November 9, 2000

Where: Holiday Inn in Downtown Providence
Promenade Room

Time: 6:00 pm to 8:00 pm

🕒 please come 15 minutes early, because we will start right at 6

We will pay for transportation and childcare

✳ ***A Light Dinner is provided*** ✳

➔ *You will be paid $50.00 for your participation in the focus group*

Please call Holly at 462-6367 if you have any questions.

☺ Sponsored by The Center for Adult Health ☺
Department of Human Services

Appendix 4: Introductory Statement

INTRODUCTORY STATEMENT

Introduce facilitator, recorder and organizer. Mention that we are working for MCH Evaluation, an outside contractor, hired by the Medicaid Program to find out how the Medicaid Program can make the program better for recipients.

Thank you for coming this evening. You are probably wondering what is a focus group? Focus groups are used to develop new services and products. For example, how to make cereal sell by testing different cereal packages. The Department of Human Services has done a series of focus groups to find out if consumers are satisfied with the medical care services they are receiving. We are interested in your experiences with medical care services such a primary and specialty medical care, dental care, mental health services and eye care. Today our group is concerned with the experiences of adults of fee-for-service Medicaid.

Your answers are private and will not be shared with anyone. I will tape this as we talk because I cannot remember everything that is said and do not want to miss any of your comments. We will listen to the tape and write down your opinions and ideas. We will not use your name. If you want to say something and don't want it recorded, we can turn the recorder off. You only have to answer the questions you want to and you may leave the meeting at any time. Remember, there are no right or wrong answers. We want to learn about your experiences with the Medicaid program and your ideas about what the Medicaid Program can do to improve services.

My job is to make sure we get everyone's best ideas and opinions. Since we have a lot of questions to answer and only two hours, I may sometimes interrupt to move us

along but I will try to bring up the other issues you raise if we have time at the end. We will take a break after one hour. At the end of the session, a representative from the Medicaid program will come to answer any questions you may have about the Medicaid Program.

Appendix 5: Recorder Notes

October 18th Focus Group on Adults with Disabilities Living in the Community
African-American Focus Group
INITIAL thoughts on the substantive issues raised in last night's focus group

In general, participants were happy with their doctors and the services they received. They were grateful for their Medicaid benefits.

Shared Issues

1. Generic Drugs

Folks were very unhappy that Medicaid pays only for generic drugs. Participants' perceptions included:

a. the quality of generic drugs is not as good as name brand drugs
b. generic drugs were not as strong as name brand drugs
c. the use of different generic drugs for the same prescription causes confusion... 'for years a person's heart medication was a pink pill, now it is a blue pill'
d. one person suggested that generic drugs are only in a 'testing phase'

2. Treatment in Emergency Departments

a. the wait is too long
b. those with blue cross/blue shield cards are serviced first
c. those with Medicaid cards are made to wait, they aren't treated with respect, they are treated as second class citizens

3. Specific doctor or facility

Participants and organizers all came to the conclusion that the greatest indicator of satisfaction was the person's doctor or the place where a person received care. The one participant who was very dissatisfied with her care was told by the other participants that she should get a new doctor and change the place where she goes for care.

4. Wait for Eyeglasses

People are made to wait a year or two for new eyeglass prescriptions even when they are having severe vision problems.

5. Wait for Dental Work

People are often made to wait for long periods before receiving the dental care they need.

6. Equipment

Getting needed equipment is not a problem. One participant expressed the view that getting rid of the equipment (a hospital bed) when no longer needed was a bigger problem.

7. Handling Depression

Participants shared the opinion that depression is something one has to handle oneself. They all seemed to have a strong aversion to the use of anti-depression drugs such as Prozac.

8. Over-the Counter medical supply costs

This was a minor point that came late in the evening when the facilitator had the participants summarize the discussion.

Participant-Specific Issues:

1. Lock-in pharmacy's

One participant has to fill his prescription at a pharmacy located far from his home.

2. Finding out about specific Medicaid benefits and services

Whereas some of the participants received written information on Medicaid benefits and services, others hadn't .

October 25th Focus Group on Adults with Disabilities Living in the Community
Hispanic Focus Group
INITIAL thoughts on the substantive issues raised in the session

1. In general, as with the folks in the African-American group, a crisis is what precipitated their enrollment in Medicaid. It was the medical provider or social worker involved in the crisis who helped them in the Medicaid enrollment process. A number of people in the group were forced to give up their jobs, either because they were too sick to continue working or in order to qualify for Welfare, to become eligible for Medicaid.

2. In the Hispanic group, the lack of health care access and coordinated primary care were more prominent issues than they were in the African-American group.

   a. Many persons had problems getting doctor's appointments.... 'we don't accept Medicaid', 'we aren't taking new patients'. This was particularly the case for psychiatric care.
   b. Folks remarked that the tone of the person answering the phone in the doctor's office would change when they said they had Medicaid coverage.... 'and this is the first question they ask you. They are more concerned about how much money you have than how sick you are.'
   c. People expressed frustration with not having one doctor. They said you spend all the appointment's scheduled time explaining your health problems, over and over again to different doctors. People also don't like being treated by 'student doctors'. They want 'real doctors.'

As with the folks in the African-American group, my general perception was that those people who have their own were much more satisfied with the care they receive; those with their own doctor have a more coordinated medical services situation.

3. Emergency Rooms

This group expressed the same experience of poor treatment in the emergency rooms (long waits) as did the African-American group. As with the African-American folks, they believe this is a result of their Medicaid status. Those with one primary care doctor, who was willing to intervene, were more able to resolve this problem. Two persons explained how after waiting 6 to 8 hours, they simply left the emergency room. One woman said she would never again go to an emergency room.

4. Generic drugs

As with the African-American folks, the members of this group also believe that the quality of generic drugs is not as good as brand-name drugs.

5. Depression

The Hispanic folks expressed greater acceptance of the benefits of professional psychiatric care than did the African-American folks.

6. Prescriptions

People think they are sometimes cheated in the amount of pills they received from the pharmacy. One person said that Medicaid does not always cover the expense of an entire prescription.

7. Wait for dental services.

Because there is a limit on how often a person can obtain a particular service such as x-rays, if a dental emergency arises which requires x-rays and a person had x-rays earlier in the year for routine purposes, that persons has to wait for needed dental care.

8. Ideas for Improving the Medicaid Program

People felt that the benefits provided by Medicaid aren't always adequate. They mentioned how sometimes one has to choose between food and medicine. They talked about having to wait to fill a prescription until they could afford to purchase what they were told was an effective amount of the medicine.

November 8th Focus Group on Adults with Disabilities Living in the Community
White Non-Hispanic Group
INITIAL thoughts on the substantive issues raised in the session

I had as much fun listening to the tape recording of this focus group as I did in participating in it. If there are any doubts of the need to communicate with these Medicaid enrollees, one need only listen to the 8 minutes of the tape which were recorded during the break. (I forgot to shut the tape off.) The level of intense involvement in the discussions which occurred during the break is truly amazing.

MAJOR ISSUE: These folks need and want information on what services and benefits are covered by the Medicaid program. They need and want to talk directly with someone who can explain Medicaid services and benefits. There needs to be a phone number to call which will be answered by someone knowledgeable about Medicaid services and benefits.

ACCESS: As with people in the other focus groups, an illness or injury precipitated enrollment in Medicaid. Usually a doctor, nurse or social worker assisted in the enrollment process. Though these people helped in the enrollment process, they were sometimes disrespectful to the patient. However, we also heard that a number of people needed to involve a lawyer to be allowed to enroll in Medicaid. (One of these folks first enrolled in Ohio.) We heard from one person that it took 2 years to qualify for Medicaid benefits.

PRESCRIPTION MEDICATION: There were many issues mentioned on this topic:

1. Being given different types of pills for the same prescription
2. Needing to see a doctor in order to get a prescription refill
3. Needing to fill a prescription within a specific time frame
4. If a refill or refills were prescribed, all refills had to be purchased at the same time. You couldn't purchase the refills at a later date. This caused financial difficulties.
5. One person wasn't able to get a specific prescription she feels she needs unless it were administered by a visiting home nurse. In this case, the medication was free!
6. Having to pay for prescribed medicine

DOCTOR: Again we heard that those with a regular doctor were more satisfied with their medical care. Those who had to see whichever doctor was available at the clinic were not satisfied. They were frustrated by having to explain their health problems over and over again to different doctors. Some have had difficulty getting their own doctor.

FREQUENCY OF DENTAL AND EYE CARE SERVICES: We heard similar complaints about having to wait to receive needed dental and eye care services.

November 9th Focus Group on Adults with Disabilities Living in the Community
INITIAL thoughts on the substantive issues raised in the session

In this focus group, there were African Americans, American Indians, an Hispanic, and a Portuguese person. Two persons had both physical and developmental problems. One person was legally blind and a few years back developed MS. The nature of one person's health problems was not clear though he had an apparent alcohol-dependency problem. The woman with HIV is enrolled in a research project and her medical care is supplied by the project or through HIV-related services. Some of these people knew each other.

It was a good group because it made clear how simplified we need to make the survey questionnaire to effectively collect information from some of the people in our population of interest.

One member of the group was disruptive during much of the session with at points other members of the group shushing him. A number of times the tape picks up his voice telling 'his woman' to stop kicking him! She was actually trying to keep him under control.

ISSUES: Many of the issues discussed in this session were similar to those in other focus groups.

1. The wait in the emergency room was too long. However, all agreed the long wait was the same for everyone no matter what their insurance.

2. For those who had their own doctor, they were satisfied with their medical care. These people seemed to be able to get the medicine they needed, didn't have to pay for their medicine, could get any equipment they needed, and their doctors intervened for them when they visited the emergency room.

3. Some folks were having a difficult time finding a doctor who would accept Medicaid patients. The blind woman who developed MS had an 'MS' doctor for a few years when first diagnosed with MS. She was happy with her care. Recently her 'MS' doctor moved to Baltimore leaving her a list of referrals. None of the referrals would accept her because she is on Medicaid.

4. People in this group also didn't have a sense of what services and benefits Medicaid covers. This was not an issue for those with their own doctors. One woman said: "I can always get whatever my doctor tells me I need."

5. Those who received their medical care at RI hospital or at clinics didn't like being treated by interns... 'I am not learning from them, they are learning from me. I feel like a guinea pig.'

6. These folks didn't express any problems with receiving generic drugs. Some didn't know what generic drugs are.

7. Similar complaints about not being able to get needed eye care services were expressed. Folks didn't seem to have problems with dental services. One focus group participant, age 30 but developmentally more like age 12, had had an accident and had to have extensive dental work. He said that he doesn't go to the dentist anymore after that, he takes care of his teeth himself. Another participant asked him what he meant by taking care of his own teeth. David said: "I brush them two times a day."

8. Two said they were locked into a particular pharmacy. However, at other points they talked about switching pharmacies.